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Community Health / Policy

Abstract Title

Deconstruct to reconstruct: dismantling conventional practices within patient engagement and reimagining reciprocal research with people with lived experience.

Background

The Pediatric Outcome imProvement through COrdination of Research Networks (POPCORN), a pan-Canadian pediatric research platform, conducted a needs assessment survey with its researchers, clinicians, knowledge users, collaborators, and patient partners. Upon completion, Patient Engagement (PE) training emerged as the most significant research education gap.

Objective

To empower through co-design methods, a patient engagement training program for clinicians, researchers, and trainees, grounded in the lived-experiences of partners facing tokenistic engagement practices.

Methods

A working group (n=27) of patient partners, clinicians, and researchers collaborated to design a 3 part online webinar series on PE. Storytelling, grounded in the lived experiences of patient partners, was used as a central educational tool. The co-creation process and resulting training content will be evaluated using an online survey in the future to identify lessons learned and inform future initiatives.

Results

The training was built around the overarching theme—Deconstruct to reconstruct: dismantling conventional practices within patient engagement and reimagining reciprocal research with people with lived experience. This theme encouraged critical reflection and creative approaches to collaboration. Three online modules were developed:

1. Deconstruct – challenging oppressive, non-inclusive, transactional, tokenistic, and paternalistic PE practices.
2. Communicate – emphasizing empathy, safe spaces, accessible language, and conflict resolution.
3. Reconstruct– building sustainable relationships with youth and parent partners, overcoming barriers, and demonstrating appreciation.

Conclusion

Co-design with patient partners enabled the development of training that moves PE beyond transactional activities toward reciprocal and inclusive practices. This work highlights the value of embedding lived experience into research education and offers a model for networks seeking to strengthen PE capacity and foster meaningful and lasting partnerships with youth and families.

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